

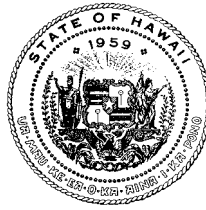
2002 Statewide Survey on Caregiving



*"E Loa Ke Ola"
May Life Be Long*

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Executive Office on Aging**

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Executive Summary

Since the creation of the National Family Caregiver Support Program under the Older American's Act, more attention has been given to support family caregivers in Hawai'i. Although family caregivers are the backbone of Hawai'i's long-term care (LTC) system, little attention has been given so far about their needs for helping their loved ones and their own well being. Thus, the Hawai'i Executive Office on Aging (EOA) contracted with the Center on Aging (COA) at the University of Hawai'i at Manoa to conduct a statewide survey of family caregivers. This report was prepared by Drs. Harumi S. Karel and Kathryn L. Braun of the Center on Aging, John A. Burns School of Medicine, University of Hawaii.

Purpose:

The purpose of this survey was to assess the demographics and needs of caregivers and to examine the effects of caregiving on caregivers and their families. In addition, EOA identified some key issues to be explored, such as quality of life of caregivers, current utilization of formal care services and perceived service needs, use of advance directives, extent of private LTC insurance coverage, support for a state-sponsored LTC insurance plan (called CarePlus), and support for new models of consumer-directed care.

Caregiver needs were examined against the seven markers or stages of caregiving—from not identifying oneself as a caregiver, through recognition of the role and need for help, to the institutionalization and death of the elder. This framework, developed by Drs. Rhonda Montgomery and Karl Kosloski, makes conceptual sense, although its authors acknowledge that not every caregiver goes through each successive stage. In this study, service use/desires were analyzed within this framework.

The definition of a caregiver in this study was a non-paid family caregiver who was providing care to the elderly 60 years old or older. "Family" was interpreted broadly, to include friends, neighbors, and volunteers, as long as the elder care was uncompensated.

Method:

The Statewide Survey on Caregiving was administered by using the mail-out survey. The questionnaire was designed based on the suggested key issues provided by the EOA. At the same time, various survey questionnaires on caregiving, which have already been utilized by different organizations or states, were examined to construct the questions. The questionnaire was written in English. The questionnaire was pre-tested, revised several times, and finalized with the consultation of the EOA staff.

Initially, the expected sample size was 2,000 family caregivers statewide hoping that 40-50% of them would respond. However, concern was raised from the AAAs regarding the rights of family caregivers to privacy. Thus, the EOA decided not to request lists of caregivers from the AAAs. Rather, we solicited participants through local media and conference presentations. A total of 896 names were solicited statewide, and the surveys were mailed out. Although the response rate was 57% (513), only 50% (445) of the responses met the criteria for the study, i.e., they were currently helping a loved one age 60 or older but they were not receiving payment for care provided.

Findings:

A. Profile of the respondents

A majority of the respondents were female, and the average age was 60 years. Fifty-three percent of the respondents were of Japanese origin, followed by Caucasians at 20%. Two-thirds of the respondents were married, and about half of them were employed. Sixty percent of respondents lived with their care

recipients. About two-thirds of the respondents were children of the care recipients, while spouses represented about 24%. Fifty-nine percent of the respondents had college or post-graduate degrees. Thus, the respondents in this study were highly educated.

B. Caregiving tasks

The average duration of their caregiving period was 5 years, and the average duration of assistance a week was 46 hours.

The five most common caregiving tasks were: 1) providing companionship, reassurance, and emotional support, 2) handling medical appointments and medications, 3) helping with housework, shopping, and meal preparation, 4) helping with transportation and walking, and 5) helping with the paperwork and bills, giving money, and paying expenses. Approximately 55% of the respondents provided personal care, helping elders with bathing, dressing, feeding, or getting to the bathroom, and 42% of the respondents were helping to change diapers and clean up when the person had an “accident.” This means that a quite number of care recipients were frail and needy.

As one might expect, the spouse tended to provide more high-level assistance, such as personal care, lifting, diaper change, than neighbors or friends. Similarly, respondents who lived with care recipients provided more high-level assistance than the respondents who did not live with their elders.

C. Well-being of the respondents and their feeling towards caregiving

In general, a majority of the respondents seemed to be well adjusted in the situation and expressed the importance of the family relationships to their well-being. Many of them felt that the family gave them some strength, and most had supportive friends. Only 27% of the respondents said they felt depressed.

Interestingly, the respondents who lived with their care recipients were more likely to report that they were depressed/not emotionally well, not happy with their lives, and not feeling financial stability. Similarly, the respondents who did not have additional help were more likely than those who were to report that they were depressed, not physically well, not getting support from their families, and not financially stable.

Although about half of the caregivers were providing labor-intensive care for their elders, many of them felt confident in providing care. Two-third of the respondents felt they were coping well with the situation, and only about one-fourth of them indicated some negative effects on their health and some strain in the relationship with family and/or social life.

D. Desires and wishes of the respondents

Although there were various wishes and desires among the respondents, most of the respondents wanted more free time for themselves and to: 1) travel, 2) engage in hobbies/leisure activities, 3) socialize or spend more time with their family members and friends, and 4) relax or sleep more to take care of themselves.

E. Formal care services and the current needs of the respondents

About 33% of the respondents were providing care without any formal care services. The major reason given for not utilizing formal services was that they did not need outside help. They felt that they could handle the situation without any formal assistance.

Among respondents who received some formal assistance, they used a combination or variety of services. The five most commonly used services were: 1) adult day care services, 2) personal care services, 3) transportation/Handivan, 4) home-delivered meals, and 5) homemaker services.

Although adult day care/respite services are considered one of the most important services to relieve caregiver burden, about two-thirds of the respondents did not utilize adult day care/respite services. Commonly expressed reasons for not utilizing adult day care/respite services were: 1) the care recipient didn't want to go, and 2) the respondent or their family members did not need outside help. This indicated that there was some hesitancy in using the adult day care/respite services.

About four-fifths of the respondents expressed that they needed some assistance or services. Although the needs of respondents in each marker or stage of caregiving differed slightly, the commonly expressed caregiver needs were for: 1) information, education, and training about caregiving, 2) health maintenance for the caregiver, such as an exercise program, 3) adult day care/respite services, 4) tax assistance (state tax deduction or credits), and 5) personal and family counseling, advice, mediation, and support groups.

Models of consumer-directed care are being tested on the mainland and are gaining in popularity. Although there has been little publicity about these models locally, most caregivers indicated that they would be interested in receiving and managing cash to buy assistive services for their elders and themselves.

F. Preparedness for the end-of-life planning

In regards to the preparedness for the end-of-life, about half of the respondents had legal documents such as wills, living trusts, advance directives, and power of attorney for themselves. For their care recipients, the preparedness was slightly higher. However, considering long-term care (LTC) insurance, two-thirds of the respondents had not purchased a plan, primarily citing concerns about cost. Caregivers most likely to have private LTC insurance were well educated Asian adults.

About 51% of the respondents were not sure about supporting a state-sponsored LTC insurance, but 35 % of the respondents endorsed the idea and were willing to pay. The median amount respondents were willing to pay was \$50 a month. Respondents also were supportive of the idea of tax credits for caregiving.

Future Directions:

Hawai'i is still in an early stage of developing a system of support for family caregivers. Although the study was not based on a representative sample of family caregivers, the results provided very useful information about caregivers, such as what they did and how they felt, in addition to their service needs. Based on the results of the survey, the EOA can focus on the development or strengthening of services that were identified as helpful for family caregivers.

Final Report

Introduction:

The Center on Aging (COA), John A. Burns School of Medicine, University of Hawai‘i at Manoa was contracted by the State Executive Office on Aging (EOA) to conduct a Statewide Survey on Caregiving between March to December 2002.

Through the National Family Caregiver Support Program (NFCSP) under the Older Americans Act (OAA), Hawai‘i’s Area Agencies on Aging have received funds to support family caregivers. EOA earmarked state funds to help develop a family caregiver support program in Hawai‘i. Although it was estimated that 114,872 informal caregivers reside in Hawai‘i¹, not much information about the informal caregivers was available upon which to base statewide program strategies.

Thus, the purpose of this survey was to assess the demographics and needs of caregivers and to examine the effects of caregiving on caregivers and their families. In addition, EOA identified some key issues to be explored:

- Quality of life of caregivers – emotional and physical well-being, family and social relationships, employment, support system, wishes and desires, etc.
- Current utilization of formal long-term care (LTC) services and perceived service needs
- Use of advance directives
- Extent of private LTC insurance coverage and support for a state-sponsored LTC insurance plan (CarePlus)
- Support for new models of consumer-directed care, through which caregivers are given cash to purchase goods/services to meet their needs as caregivers

Finally, caregiver needs were examined against the seven markers or stages of caregiving stipulated by Drs. Rhonda Montgomery and Karl Kosloski.² These stages were determined through long-term observation of caregivers of frail elders, many with dementia, and include: 1) the performing of care without identifying themselves as caregivers, 2) self-definition as caregiver, 3) provision of personal care, 4) the seeking out or using of assistive services, 5) consideration of institutionalization, 6) actual nursing home placement, and 7) termination of the caregiving role. Although it is acknowledged that not every caregiver goes through each successive stage, this framework makes conceptual sense. In this study, service use/desires were analyzed within this framework.

This report was prepared by Drs. Harumi S. Karel and Kathryn L. Braun of the Center on Aging, John A. Burns School of Medicine, University of Hawaii.

Methods:

The Statewide Survey on Caregiving was administered by using mail-out surveys. The questionnaire was designed based on the suggested key issues provided by the EOA. At the same time, various survey questionnaires on caregiving, which have already been utilized by different organizations or states, were examined to construct the questions.

¹ Arno, P., & Memmott, M. (1999). Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, in Feinberg, L.F., Newman, S.L., and Steenberg, C.V. (2002). Family Caregiver Support: Policies, perceptions and Practices in 10 States Since Passage of the National Family Caregiver Support Program.

² Montgomery R. J. V. and Kosloski, K. (2000). Family Caregiving: Change, Continuity and Diversity. Retrieved July 16, 2001 from <http://www.aoa.gov/carenetwork/Montgomery-kosloski.html>.

In addition, EOA was interested to find out the needs of caregivers who were in different stages of caregiving. As stated above, caregivers go through different experiences at different times (markers) in their caregiving efforts. Their needs may change depending on which stage of caregiving they are at, from marker 1-performing caregiving tasks without identifying themselves as caregivers to marker 7 – termination of the caregiving role. Thus, some of the questions were developed to determine the “stage of caregiving” of each caregiver participating in the survey. The questionnaire was written in English, and no translation to other languages was available. It was pre-tested with caregivers at the Palolo Chinese Homes-Eldercare Services that provides adult day care/respite service and at the Kapahulu Senior Center.

The key issues, a draft survey questionnaire, and the methodology were shared with the Area Agency on Aging (AAA) to solicit their opinions about the statewide survey and to seek their collaboration in conducting the survey.

Sample Selection

Originally, the selection of the sample population was based on two separate methods: 1) a random selection of caregiver names from the AAA’s client lists and 2) convenience sampling through solicitation of caregivers by newspaper advertisement and flyers. For the solicited participants, a family caregiver’s health guide was given free of charge as a token of appreciation.

Initially, the expected sample size was 2,000 family caregivers statewide hoping that 40-50% of them would respond. However, the concern was raised from the AAAs regarding the rights of family caregivers to privacy. Although the AAAs had permission to release clients’ names for purposes of program evaluation, they didn’t have permission to release caregiver names. After much discussion, the EOA decided not to request lists of caregivers from the AAAs. Therefore, we had to obtain our entire sample through solicitation by newspaper advertisements and flyers, through the EOA Family Caregiving Network, and through caregiver meeting and conferences.

An advertisement to recruit caregivers was placed twice in local newspapers in each county in late July and early August 2002. In addition, the recruitment of caregivers was done during caregiver conferences organized in Honolulu, Hawai‘i, and Maui counties. Approximately 3,000 flyers inviting participation were distributed to the clients of the Area Agency on Aging in each county.

The definition of a caregiver in this study was a non-paid person providing help to another. This could include an elder’s family member, friend, neighbor, or even a volunteer. To be eligible for inclusion in the study, caregivers must be:

1. Helping or providing care to a family member, relative, or friend age 60 or older with some physical and/or mental limitations, either now or in the past 2 years, and
2. Providing care without any payment.

A total of 438 names were solicited statewide (243-Honolulu, 84-Hawai‘i, 54-Maui, 57 –Kaua‘i) and another 161 names were obtained through the EOA family caregiver network list. Later, the AARP agreed to mail fliers to participants who attended its Caregiver Conference held in July 2002, which included 349 names of individuals residing in Honolulu County. Duplication of names was checked, and the final count was 910 unduplicated names (438 solicited, 137 from the EOA list, and 335 from the AARP list). Fourteen surveys came back as non-deliverable. Thus, 896 surveys were mailed out successfully.

Results:

A total of 513 people returned the survey for the response rate of 57% (513 out of 896), but 68 cases did not meet the criteria of the study because they were either paid caregivers, the care recipients were less than 60 years old, or they had stopped providing care more than 2 years ago. Thus, the number of respondents who qualified for inclusion was 445: Hawai'i County – 52 (12%), Honolulu County – 328 (73%), Kaua'i County – 29 (7 %), and Maui County – 36 (8%). The county distribution of respondents is quite similar to the distribution of the elderly population in Hawaii: Hawai'i County -13%, Honolulu - 73%, Kaua'i - 5%, and Maui - 9%.

It should be noted that there were quite a number of missing responses, meaning that not every caregiver answered every question. Thus, numerators and denominators are provided, along with percentages, for items reported below.

Profile of the Respondents:

- Age: The average age of respondents was 60 years, but the range was 25 to 90 years.
- Gender: 81% (354 out of 436) were female, and 19% (82) were male.
- Ethnicity: 53% (203) were Japanese, followed by 20% (86) Caucasian, 11% (49) Hawaiian/Part-Hawaiian, 9% (40) Chinese, and 5% (23) Filipino (Table 1).
- Marital Status: 69% (302 out of 437) were married, followed by 13% (58) single, 11% (47) separated, and 7% (30) widow (Table 2).
- Employment: 42% (179 out of 432) of the respondents were retired, followed by 32% (137) full-time employed, 12% (53) part-time, and 15% (63) not employed (Table 3).
- Education: 59% (127 out of 435) had college or post-graduate degrees, followed by 22% (97) some college, 16% (71) high school degree, and 3% (11) some high school (Table 4).

Family Relationships:

- 66% (291 out of 442) of the respondents were children who were taking care of their parents. Their average age was 55. Of adult child respondents, 55% (158 out of 287) were living with their parents who needed care and 45% were living elsewhere.
- 24% (104) were spouses. Their average age was 73.
- 7% (32) were other relatives such as siblings, grandchildren, niece, etc. (Table 5).

Although not everyone responded, 77% (328 out of 429) of the respondents said they did not have any dependent children, followed by 11% (47) with one dependent child, 9% (38) with two dependent children, and 4% (16) with three or more children (Table 6). The age range of dependent children was from 1 to 58 years old, including 12% respondents who reported having dependent children over 40 or older. Because we did not define the term “dependent,” it is unclear if these dependent adult children (those older than 21) had disabilities, if they were just perceived as dependent because they were living with their parents, or if caregivers misunderstood the question and just listed the ages of all their children.

Sixty percent (261 out of 435) of the respondents lived with their care recipients (including 158 adult children and most of the 104 spouses). Thirteen percent (56) of the respondents stated that their care recipients was living independently, 12% (52) lived with spouses, 7% (31) lived with other family members, and 8% (35) lived in care facilities (Table 7).

Caregiving Stage and Tasks:

The items used to identify different stages of caregiving tasks were:

- Are you currently helping, keeping an eye on, or providing care to someone who is 60 years old or older and who has some physical and/or mental problems?
- Do you consider yourself a “caregiver?”
- Which kind of help do you provide? – Helping the person with bathing, dressing, feeding, or getting to the bathroom?
- Is the person you care for currently receiving any of the following services? – list provided
- I consider placing him/her in a care facility.
- Where does he/she live? – in a care home, nursing home or assisted living facility

In regards to the different stages of caregiving developed by Dr. Montgomery, it was very difficult to accurately calculate the percentage and the number of caregivers who matched the stated stages. The reasons were: 1) not everyone answered the key question that identified different stages and 2) caregivers were ambivalent on the item about nursing home placement, reporting that they “sometimes consider it.” We deleted cases with missing and/or ambiguous data related to the seven stages, leaving 376 caregivers that we could stage:

- 6% (22 out of 376) of the respondents were in Marker 1 – Performing caregiving tasks without identifying themselves as caregivers
- 19 % (72) were in Marker 2 – Just beginning to identify themselves as caregivers
- 13% (47) were in Marker 3 – Performing personal care
- 33 % (124) were in Marker 4 – Receiving assistance and using formal service
- 10% (39) were in Marker 5 – Considering nursing home replacement
- 6% (24) were in Marker 6 – Their elder was institutionalized.
- 13% (48) were in Marker 7 – Their elder had recently died. (Table 8).

Although we could determine caregiver stage for only 376 caregivers, 445 respondents answered questions related to the caregiving tasks that they performed. Of these, 89% (396) were currently providing care to their loved ones. Among caregivers who stopped providing care, 80% (37 out of 48) had stopped because of the death of their loved ones. Seven percent (3) mentioned that the care was terminated due to the relocation either by the caregiver or the care recipients, and 4% (2) mentioned that their loved ones had recovered and no longer required care. One person indicated that her loved one went into a nursing home.

The following information includes the characteristics of current caregivers and the caregivers who terminated their caregiving tasks within 2 years. Although not everyone responded to the question, 94% (410 out of 436) of the respondents identified themselves as caregivers, and 6% (26) did not.

Among a total of 395 who responded to the question about the time spent for providing care, the average duration was 5 years, ranging from 1 month to 30 years. The average duration of assistance a week was 46 hours, ranging from 1 hour to 200 hours. Seven percent (29) of the respondents felt that the caregiving was a 24-hours task or more. Eleven percent (50) of the respondents did not answer this question. Though the reasons for not answering this question were speculative, it might be that the caregiving tasks could not be measured by hour of tasks only or it was difficult to calculate because the type and hours of assistance provided might vary from day to day.

Ninety-eight respondents, approximately 22% of the total, stated that they didn’t have anybody to help in their caregiving tasks. However, a majority of the respondents had at least someone to help provide care. Children were the most frequently mentioned source of assistance, followed by siblings, spouse, other relatives, and neighbors (Table 9). Among other relatives, almost half of them mentioned that the grandchildren were the source of additional assistance. One hundred twelve respondents, approximately

25% of the total, were using paid services such as adult day care, nursing home without walls, PACE, etc.

Although the type of caregiving assistance varied among respondents, a majority of them provided a combination of various tasks. The five most common forms of assistances were

- Providing companionship, reassurance, and emotional support - 89% (397 out of 445)
- Handling medical appointments and medications –88% (392)
- Helping with housework, shopping, and meal preparation – 87% (386)
- Helping with transportation and walking – 80% (356)
- Managing paperwork and bills, giving money, and helping pay expenses – 76% (338) (Table 10)

In addition:

- 55% (246 of 445) of them assisted elders with bathing, dressing, feeding, or getting to the bathroom.
- 42% (186) were assisting with changing diapers and cleaning up when the person has an “accident”
- 29% (128) of them assisted with lifting of the loved ones.

This means that a significant number of respondents provided personal care and other high-level assistance, including diaper change, indicating that their care recipients were frail and needy. Some of the other activities mentioned were: 1) socialization, 2) advocacy, 3) exercise/physical therapy, 4) massage, 5) yard work, and 6) tasks that required nursing skills.

As one might expect, the spouse tended to provide more high-level assistance (personal care, lifting, diaper change) than did neighbors or friends, 66.0 % vs. 27.3 %. Additionally, respondents who lived with care recipients provided more high-level assistance than respondents who did not live with them. These differences were statistically significant ($X^2 = 50.961$, $p < .000$) (Table 11).

Twenty-nine percent (127 out of 445) of respondents indicated that they did not need any outside help, but about 71% (318) of the respondents said they needed help. The three most common periods for needed assistance were: 1) during their vacation time- 58%, 2) during times of crisis – 55%, and 3) during weekends or holidays – 34%. During the 24-hour period, the preferred time period for assistance was in the morning. Overnight assistance was requested by 64 respondents, about 20% of the subgroup of respondents indicating a need for assistance (Table 12).

Emotional Conditions of the Respondents:

A. Feelings toward caregiving

The total of 16 questions was asked about how caregivers felt about providing care to their loved ones. There were quite a number of missing responses for these questions. Among the caregivers who responded:

- 74% (313 out of 421) felt confident in providing care, and 3% (11) indicated no confidence. The rest of them were in between.
- 61% (253 out of 414) felt they were coping well with the present situation, whereas 7% (29) felt that they were not coping well.
- 59% (240 out of 408) felt that they were doing more than their share of caring compared to other family members or other members of their support system.
- 35% (147 out of 416) of the respondents indicated that taking care of loved ones put a strain on their social life, 25% (104 out of 419) felt it put a strain on their family relationships, and 20% (83 out of 418) felt it put a strain on their relationship with loved ones.
- 25% (101 out of 410) felt that the caring had negative effects on their physical health.

- 24% (99 out of 415) felt caring took all of their time.

Twenty percent (79 out of 386) of the respondents felt that they should be doing or should have done more to provide care, whereas 49% (190) indicated otherwise. This item had the most missing data of all 16 questions that asked about feelings. In retrospect, this item is potentially guilt-provoking and should not be included in future surveys.

Twenty-seven percent (110 out of 406) of the respondents felt that caring for their loved ones affected their retirement plans. These respondents were much more likely to be retired or not employed (vs. employed) ($X^2=21.315$, $p<000$) (Table 13). On the other hand, employed respondents were less likely than non-employed respondents to feel comfortable handling all of their family responsibilities ($X^2=8.820$, $p=003$) (Table 14).

Twenty-seven percent (112 out of 412) of respondents felt that caring affected them financially. Although 21% (84) of the respondents sometimes considered placing their loved ones in a care facility, only 12% (49) indicated that they were really thinking about it (Table 15).

Among the respondents who were employed, 44% (90 out of 205) of them stated that they used some type of leave for caregiving, 28% (58) stated that they had to reduce their work hours, 25% (50 out of 199) stated that they felt less productive and more distracted, but only 13% (26 out of 203) stated that they were thinking of quitting their job to care for this person (Table 16). The respondents who felt less productive and more distracted tended to be more depressed ($X^2=13.548$, $p=001$) (Table 17).

B. Self assessment of overall well-being

The majority of caregivers reported that they were doing fairly well emotionally. For example:

- 79% (325 out of 412) that they were happy with their lives.
- 80% (321 out of 402) felt emotionally well.
- 75% (299 out of 399) felt physically well.
- 73% (272 out of 372) were not depressed
- 69% (274 out of 395) could comfortably handle all his/her family responsibilities
- Only 7% (26) of them said they had increased intake of alcohol and/or cigarettes since becoming a caregiver.

On the other hand, about a quarter of them were not doing well, e.g., 93 (21%) were not happy with their lives, 111 (28%) were not comfortable handling all their family responsibilities, and 100 (27%) were depressed. Additionally, 53% (212 out of 398) of them felt they were not doing enough to take care of themselves.

In regards to family relationships, 90% (372 out of 414) of the respondents enjoyed spending time with their families, and 69% (274 out of 395) felt comfortable handling all of their family responsibilities. Eight percent (324 out of 407) felt that their family gave them strength.

Ninety-one percent (368 out of 406) of the respondents stated that they had supportive friends. Sixty-six percent (268 out of 409) of them felt financially stable.

Therefore, approximately three-fourths of the respondents seemed to be emotionally and physically well and felt confident in taking care of the loved ones. However, 28% of them felt that they were not handling all the responsibilities well, and 53% felt that they were not doing enough to take care of themselves. Although about one-fourth of them felt that caregiving had put some strain on their social and family relationships, a majority of them enjoyed spending time with their families and felt that the family gave them strength (Table 18). Although few caregivers had dependent children, those that did

were less likely than those who did not to feel financially stable, and the more dependent children the respondents had, the less financially stable they felt ($X^2=14.000$, $p=.001$) (Table 19).

Table 20 presents correlation coefficients for items related to emotional status to gain further insight into the impact of depression. Depression correlates significantly with all the other items. Tables 21 – 23 also show that depressed respondents are more likely than non-depressed respondents to feel negative about their life ($X^2=105.786$, $p<.000$), to feel physically unwell ($X^2=86.211$, $p<.000$), and not to enjoy being with family ($X^2=14.930$, $p=.001$).

In addition, the respondents who were providing care without any other help tended to feel more negative about:

- Emotional well-being ($X^2=11.483$, $p=.001$)
- Support from family ($X^2=11.483$, $p=.001$)
- Financial stability ($X^2=8.086$, $p=.004$)
- Depressed ($X^2=11.196$, $p=.001$)
- Physical well-being ($X^2=8.923$, $p=.003$) (Table 24)

The respondents who had additional help with caregiving were more likely than those who did not to have guilt feelings about caring ($X^2=9.438$, $p=.009$) (Table 25), but they were less likely to feel strain in their relationship with their care recipients ($X^2=9.719$, $p=.008$) (Table 26). They also were more likely to feel that they were doing more than their share of caring compared to other members of their families ($X^2=16.81$, $p<.000$) (Table 27).

The effects of living arrangement on the well-being of the respondents were examined. The respondents who lived with the care recipients were:

- More likely to feel unhappy with their lives ($X^2=11.268$, $p=.001$),
- Less likely to feel that they not doing enough to take care of themselves ($X^2=7.731$, $p=.005$)
- More likely to feel unwell emotionally ($X^2=14.997$, $p<.000$)
- More likely to feel unstable financially ($X^2=6.917$, $p=.009$)
- More likely to feel depressed ($X^2=12.814$, $p<.000$) (Table 28)

C. Wishes and desires

Although there were various wishes and desires among the respondents, most of the respondents wanted more free time for themselves and to: 1) travel (158), 2) engage in hobbies/leisure activities (111), 3) socialize or spend more time with their family members and friends (108), and 4) relax or sleep more to take care of themselves (66).

Examples of desires expressed by respondents include:

- To be able to make plans and stick to it
- Be more patient with my husband and not be emotionally upset
- Feel confident and free to leave my house to do such things I enjoy
- Sleep through the night without having to give care
- Get a break from the daily chores of taking care of them
- Going on dates with my wife
- Spend longer vacations with wife without having to worry about parents and aunt
- Be ready for a happy death in 5-10-15 weeks, months, or years
- Have someone else care for him for a complete hours a day
- Spend happy, relaxing times with mother-in-law rather than only taking care of needs

Formal (paid/subsidized) Assistance:

Several items asked about formal care services, but not every item was answered by every caregiver. Among those who responded, 77% (273 out of 353) of them knew how to get information about community services to help their loved ones, but 23% (80) of them did not.

The respondents who had additional help knew more about how to get service information than the respondents who did not have additional help ($X^2 = 16.270$, $p < .000$) (Table 29).

Thirty-three percent (119 out of 358) of respondents were providing care without any formal assistance. The five most common reasons for not utilizing formal assistance were:

- I did not need outside help – 94% (112)
- I did not know what services were available – 57% (68)
- I did not have money to pay for services – 48% (57)
- I did not want strangers to come into my house – 39% (46)
- I did not know how to get information about the services – 34% (40).

Among “other” categories, the most frequently mentioned response was that the care recipients or family members refused receiving services (21). Seven said they didn’t qualify for or didn’t think they qualified for services.

Respondents who received some formal assistance used a combination or variety of services. The five most common services the care recipient received were:

- Adult day care services – 36% (85)
- Personal care services – 30% (71)
- Transportation/Handivan – 28% (66)
- Home-delivered meals – 26% (63)
- Homemaker services – 22% (52).

Although the question was asked about the frequency of services they received, very few people answered these items. Among those who responded, the average frequency of services they received for adult day care center was 3.7 times a week, 4.3 times for personal care services, 2.8 times for transportation, 4.2 times for home-delivered meals and 3.5 times for homemaker services (Table 30).

The five most common ways of finding out the services were: 1) family members and friends – 42% (115 out of 277), 2) community-based service providers, including social workers – 34% (93) 3) brochure/pamphlet/flyer/newsletter – 30% (82), 4) doctors/nurses – 27% (75), and 5) information and referral services at the Area Agency on Aging – 23% (63).

A. Adult day care/respite services:

Thirty-one percent (133 out of 435) of the respondents have or had utilized adult day care/respite services, and 69% (302) of them did not. Among the respondents who did not utilize adult day care/respite service, the five most common reasons were: 1) the care recipient didn’t want to go (155), 2) the respondent or their family members did not need outside help (107), 3) the service was expensive (69), 4) I didn’t know about adult day care/respite services (47), and 5) I didn’t have time to take the person to the program (23).

Current Needs of the Respondents:

Sixteen percent (69 out of 445) of the respondents stated they didn't need any services to help them but 84% (376 out of 445) of them indicated that they needed some assistance for themselves. Among respondents who expressed their needs, the five most common services they needed were

- Information, education and training about caregiving – 47 % (176)
- Health maintenance such as exercise program –38 % (142)
- Adult day care/respite services – 37% (141)
- Tax assistance – 32% (122)
- Personal and family counseling, advice, mediation, and support groups – 30% (112) (Table 31).

The Needs of the Respondents Based on Caregiver Stage (Marker):

As mentioned above, 6% (22 out of 376) of the respondents were in Marker 1 – Performing caregiving tasks without identifying themselves as caregivers, 19 % (72) were in Marker 2 – Self-identification as caregiver, 13% (47) were in Marker 3 – Performing personal care, 33 % (124) were in Marker 4 – Assistance and formal service use, 10% (39) were in Marker 5 – Consideration of nursing home replacement, 6% (24) were in Marker 6 – Institutionalization, and 13% (48) were in Marker 7 – Termination of caregiving tasks (Table 32).

Among respondents who didn't identify themselves as caregivers (Marker 1), the five most commonly expressed needs were:

- Information, education and training about caregiving (9)
- Health maintenance such as an exercise program (6)
- Homemaker/chore services (6)
- Personal and family counseling, advice, mediation, and support groups (4)
- Senior companion (4) (Table 33).

The five most commonly expressed needs among the respondents who identified themselves as caregivers (Marker 2) were:

- Information, education and training about caregiving (28)
- Health maintenance such as exercise program (22)
- Personal and family counseling, advice, mediation, and support groups (15)
- Adult day care/respite service (15)
- Tax assistance such as state tax deduction or credits (14)

The respondents who provided personal care (Marker 3) expressed their needs as:

- Information, education, and training about caregiving (18)
- Tax assistance such as state tax deduction or credits (18)
- Adult day care/respite service (17)
- Health maintenance such as exercise program (17)
- Senior companion (15)

The five most commonly expressed needs among the respondents who were using formal care services (Marker 4) were:

- Information, education, and training about caregiving (54)
- Tax assistance such as state tax deduction or credits (38)
- Adult day care/respite service (37)
- Health maintenance such as an exercise program (35)
- Senior companion (32)

Among respondents who were considering placing their loved ones in a care facility (Marker 5), their commonly expressed needs were:

- Adult day care/respite care services (24)
- Information, education, and training about caregiving, (19)
- Health maintenance such as an exercise program (19)
- Homemaker/chore services (16)
- Care plan service (16)

The respondents who stated that their loved ones were already in care facilities (Marker 6) expressed their five common needs as:

- Personal and family counseling, advice, mediation, and support groups (11)
- Information, education and training about caregiving (11)
- Health maintenance such as an exercise program (11)
- Financial and legal consultation (10)
- Financial support (9)

Among respondents who already terminated their caregiving tasks (Marker 7), 42% (20) of them expressed that they did not need any assistance and 58 % (28) of them did. Among respondents who expressed their needs, their common needs were:

- Information, education and training about caregiving (11)
- Homemaker/chore service assistance (10)
- Tax assistance such as state tax deduction or credits (9)
- Financial consultation (8)
- Home modification (8)

Thus, throughout the caregiving tasks, the majority of the respondents wanted more information, education, and training about caregivers followed by health maintenance program such as an exercise program for themselves.

In addition, the respondents who lived with their care recipients wanted more adult day care/respite services - 40% (104 out of 261), followed by information, education, and training about caregiving – 38% (98) than any other services. Respondents who did not live with their care recipients wanted more information, education, and training about caregiving – 45% (62 out of 139), followed by personal and family counseling, advice, mediation, and support groups – 25% (35). The respondents whose loved ones were already in institutional settings wanted more financial consultation, health maintenance programs, and information, education, and training about caregiving – 37% (13 out of 35 for each of these three services).

Advanced Planning for End-of-Life Care:

The percent of respondents who had end-of-life care legal plans for themselves were: 1) will – 62% (248 out of 399), 2) living trust – 53% (217 out of 408), 3) advance directives - 52% (190 out of 367), 4) power of attorney – 52% (210 out of 403), and 5) funeral arrangements – 36% (142 out of 391) (Table 34).

The percent of care recipients who had advanced end-of-life care legal plan were: 1) will – 75% (294 out of 391), 2) living trust – 65% (253 out of 392), 3) advance directives - 66% (252 out of 380), 4) power of attorney – 74% (298 out of 401), and 5) funeral arrangements – 60% (233 out of 389) (Table 35).

Long-Term Care Insurance

As far as the long-term care (LTC) insurance was concerned, 32% (141 out of 435) of the respondents stated that they had LTC insurance and 68% (294) didn't have. The major reason for not having LTC insurance was that they couldn't afford it or thought it too expensive (52%). Additional 14% (34) said it was too early to think about it, 10% (26) were considering it, and 8% (20) didn't know much about it (Table 36).

Individuals who had purchased LTC insurance were most likely to be Asian ($X^2 = 18.958$, $p=000$) (Table 37) and college educated ($X^2 = 11.161$, $p=001$) (Table 38).

Fifty-one percent (212 out of 419) of the respondents were not sure about paying into a state-sponsored LTC insurance plan. However, 35% (145) stated they definitely were willing to pay while 15% (62) stated they were not willing. Among the respondents who were willing to pay into a state-sponsored LTC insurance, the average amount they felt reasonable was \$70 per month, ranging from \$5 to \$ 500 per month. The median amount was \$50 per month (Table 39).

There were no significant differences toward the preference about state-sponsored long-term care insurance by ethnicity, age, gender, marital status, employment, or education.

Consumer Directives:

The respondents were asked this question: "If the person you care for were to receive \$1,000 for services a year, which arrangement would you prefer?" A number of options were given. For the 85% (379) of the respondents who answered this question:

- 57% (214) stated that they would like to receive cash to use as needed for the person they were caring for and they were willing to manage the cash themselves.
- 18% (67) stated that they would like assistance from professionals in finding and paying caregivers.
- 17% (63) stated that they preferred to receive coupon for services of their choice from participating providers (Table 40).

There were no significant differences in the preference for consumer direction by ethnicity, age, gender, employment, marital status, or education.

Advice for New Family Caregivers:

Seventy-six percent (336 out of 445) of the respondents provided advice to the new family caregivers. Although there were numerous suggestions for the new family caregivers, the five most common suggestions were: 1) ask for help or accept help from other family members, friends, professionals – 29% (97), 2) take time out from caregiving and take care of yourself – 24% (81), 3) be patient, be compassionate – 21% (71), 4) attend caregiver support group and/or gain knowledge about caregiving – 17% (53), and 5) plan carefully for financial, legal, and other need – 10% (32).

Some examples of suggestions mentioned by the respondents (as written exactly in the survey)

- Make a plan for yourself in the event you can no longer care for our loved ones.
- Keep a sense of humor.
- Talk to other caregivers before accepting to be a caregiver yourself. Be sure you know what financial, emotional, and physical demands caregiving will demand of you, especially if you need to care for more than one person as I do. Alzheimer's disease and severe senility are so misunderstood these days!

- Self matters/take care of yourself first, and feel emotionally and mentally good, and then, you can take care of another person. Simplify your own life, subtract all non-essential way of life, and live within your means/no debt.
- It is going to change your lifestyle so be willing to make a long-term commitment.

Limitations:

The study's major limitation relates to sampling. We had hoped to survey caregivers of clients receiving services through Kupuna Care and other AAA-funded programs. However, concerns for caregiver privacy blocked use of this pool of caregivers. We tried to increase solicitation of caregivers through other sources, e.g., conferences. Permission was received from AARP to mail surveys to participants at their July 2002 Caregiver Conference cosponsored by AARP and the Elderly Affairs Division in Honolulu, but this took time. Assistance also was sought from several union organizations to include information about the statewide survey in their newsletters; however, it was not successful because of the timing, i.e., the request was made too late to meet the deadline for printing their newsletters. Therefore, we basically had to rely on a convenience sampling, which had many statistical limitations. The sample size was also very small for a statewide survey. Sampling issues also delayed the administration of the survey from August 2002 to October 2002.

The second limitation was the construction of the questionnaire itself. The caregiver markers postulated by Dr. Montgomery extended from early caregiving stage to the termination of the caregiving role. Therefore, the use of present or past tense in creating each question caused some problems in developing the questionnaire. We decided to use present tense with some instructions for people who terminated their caregiving role, but this may have caused confusion.

Summary and Discussion:

As previously stated, the estimated number of informal caregivers in Hawai'i was 114,872. Despite the number of caregivers available in Hawai'i, it was very difficult to recruit a large number of caregivers for the statewide survey. Possible reasons for the difficulty in recruiting were:

1. Caregivers don't recognize themselves as caregivers. They are just family members helping other family members.
2. Caregivers might be so overwhelmed with caregiving tasks that they didn't want to be bothered.
3. They simply didn't like to be surveyed.
4. The questionnaire was too long (a total of 5 legal size pages).
5. The questionnaire was not translated into any other languages.
6. Our recruitment methods, through newspaper and conference solicitation, were ineffective.

Quite a number of duplicated names were noticed among the sign-up lists at caregiver conferences and the lists obtained from the EOA caregiver network, the AARP-sponsored caregiver conference, and caregiver support groups. This indicated that the caregivers who sought information and assistance tended to utilize several available venues. That we only reached 864 caregivers out of an estimated 114,872 informal caregivers in Hawai'i suggests that most caregivers are hidden in society.

Anecdotal reports from other caregiver programs suggest similar difficulty in recruiting caregivers. The leading problem perceived by many mainland providers is that caregivers do not see themselves as caregivers or in need of any special help or attention. In fact, national caregiver surveys have not done much better than we did. Sample sizes for surveys sponsored by the National Alliance for Caregiving

were 754 in 1987 and 1,509 in 1997. A study conducted by J. Patrick and others³ included only 841 caregiver participants even though these investigators had a recruitment budget of \$50,000 and a 30-month recruitment window.

According to AARP Public Policy Institute information⁴, the average caregiver in the U.S. is a 46-year-old woman who was married and employed outside the home. Our sample was very different—it was older (average age = 60 years) and fewer than half of the respondents were employed outside the home. Our respondents also were highly educated; almost 60% had college degrees. Since it was a mail-out survey and wasn't translated into other languages, the administration of the survey method itself might have limited the participation of some caregivers. Thus, the sample population of the survey was not representative and not generalizable, and a strict comparison to the national data cannot be made.

Due to the nature of the recruitment method, a majority of our respondents identified themselves as caregivers. A majority of them had assistance from their families and relatives. In addition, about 40% of the respondents were providing labor-intensive care that involved personal care and lifting.

Although their caregiving tasks involved labor-intensive care, many of them felt confident in providing care to their care recipients. Two-thirds of the respondents felt they were coping well with the situation, and only about one-fourth of them indicated some negative effects on their health and some strains in the relationship with family and/or social life. However, the respondents who provided care without any assistance were more likely to feel depressed, unwell physically, unsupported by families, and unstable financially. Additionally, respondents who lived with the care recipients were less likely to feel happy with their lives, emotionally well, financially stable, and that they were doing enough to take care of themselves.

The common source of information obtained about the available services was through word of mouth from families and friends. The second most common source was community service providers. The respondents who had additional help were more knowledgeable about available services than the respondents without any additional help. Although the adult day care/respite services are considered one of the most supportive services for caregivers to relieve their caregiver burdens, not many people were utilizing the services. Similar findings were noted in the study done by Hanson in Washington.⁵ He stated that the lack of utilization was due to: 1) lack of information about the program, 2) expense, and 3) difficulties in arranging assistance at a suitable time. However, in examining the results of the study in Hawai'i, the prohibiting factor from utilizing the service might be the attitude about the adult day care/respite services. The common reasons for not using the service were that the care recipients or caregivers and their family members did not want to use the services. The study done by Lingsom⁶ indicated that the adult day care/respite meant that the care recipient was being "sent away". Therefore, the caregiver might experience a guilty conscience in using adult day care/respite services.

Hawaii's population is comprised of about 20 different ethnic groups, mostly from Asia and the Pacific Islands. Traditionally, caregiving was a family affair in Asia-Pacific countries, and it was expected that the children would take care of their parents and in-laws when they became frail. Thus, they might feel guilty for abandoning their caregiving duties by sending their frail parents to adult day care/respite services. The same thing could be said for the spouse caregivers.

³ Patrick, J.H., Pruchno, R. and Rose, M.S. (1998). Recruiting Research Participants: A Comparison of the Costs and Effectiveness of Five Recruitment Strategies, *The Gerontologist*, Vol. 38 (2): 295-302.

⁴ Pandya, S.M. and Coleman B. (2000). Caregiving and Long Term Care. Public Policy Institute, AARP. Retrieved March 15, 2002 from <http://www.aarp.org/health/fs82Caregiving.html>.

⁵ Hanson, D. (2002). Listening to Caregivers: The Role of Needs Assessment in Program Planning, Retrieved April 2, 2002 from <http://www.aoa.gov/carenetwork/HansonMonograph.html>.

⁶ Lingsom, S. (1997). The Substitution Issue: Care Policies and their Consequences for Family Care, Norwegian Social Research, Nova-Rapport 6/97.

Another factor mentioned by Lingsom was the resistance to change by the care recipient. If the care recipient was unwilling to use the service, then the caregivers could not experience the feeling of respite. According to the EOA information, about 44% of elderly 60 years and older in Hawai'i use a language other than English at home, and one out of 5 of them was foreign born. Therefore, the hesitancy by the elderly to utilize the services may be due to language and communication barriers, different cultural values, and customs. These barriers are constant challenges for Hawaii's service providers.

In regards to the preparedness for the end-of-life, about half of the respondents had legal documents such as wills, living trusts, advance directives, and power of attorney for themselves. For their care recipients, the preparedness was slightly higher. However, considering long-term care (LTC) insurance, two-thirds of the respondent had not purchased a plan, primarily citing concerns about expense. Individuals with private LTC insurance were more likely to be Asian and college educated than individuals without private LTC insurance.

The state-sponsored LTC insurance plan (CarePlus) was introduced in 2002 legislative session, but it did not pass. The survey results indicated that a third of caregivers are willing to support a program like CarePlus, and only 15% stated that they were not willing to pay. More than half, however, were undecided. With this high level of uncertainty among such an educated group of caregivers, we suspect that much more publicity is needed about LTC costs, private insurance, and CarePlus if this type of program is to gain broad public support.

Models of consumer-directed care are being tested on the mainland and are gaining in popularity. Although there has been little publicity about these models locally, most caregivers indicated that they would be interested in receiving and managing cash to buy assistive services for their elder and themselves.

Many respondents expressed that obtaining information, education, and training about caregiving would help them. At the same time, they wanted some exercise-related programs to maintain their health. Without a healthy body, it is not possible to continue providing care. In examining the needs of the respondents in different stages of caregiving, the needs varied among different caregiver stages. However, regardless of the caregiver stages that the respondents were in, the commonly expressed current needs were: 1) obtaining information, education, and training about caregiving, 2) health maintenance such as an exercise program, 3) adult day care/respite services (except Marker 6 & 7), 4) tax assistance (state tax deduction or credits), and 5) personal and family counseling, advice, mediation, and support group.

Hawai'i is still in an early stage of developing a system of support for family caregivers. Although the study was not based on a representative sample of family caregivers, the results provided very useful information about caregivers such as what they did and how they felt, in addition to their service needs. Based on the results of the survey, the EOA could focus on the development or strengthening of services that were identified as helpful for the family caregivers.

Data

Table1: Ethnic Composition of the Respondents

Ethnicity	Percent (number)
Japanese	46.6 % (203)
Caucasian	19.7 % (86)
Hawaiian/Part-Hawaiian/Mix with Hawaiian	11.2 % (49)
Chinese	9.2 % (40)
Filipino	5.3 % (23)
Korean	1.4 % (6)
Hispanic	0.7% (3)
Others (Pacific Islander, Afro-American, Native American, Mix w/o Hawaiian)	5.9 % (26)
Total	100% (436)

Table 2: Marital Status

Status	Percent (number)
Married	69.1% (302)
Single	13.3 % (58)
Separated	10.8 % (47)
Widow	6.9 % (30)
Total	100% (437)

Table 3: Employment Status

Employment	Percent (number)
Retired	41.4% (179)
Full-time employment	31.7% (137)
Part-time employment	12.3 % (53)
Not employed	14.6 % (63)
Total	100% (432)

Table 4: Educational Attainment

Educational Attainment	Percent (number)
College graduate	29.7 % (129)
Post graduate	29.2 % (127)
Some College	22.3 % (97)
High school	16.3 % (71)
Less than high school	2.5 % (11)
Total	100 % (435)

Table 5: The Relationship with Care Recipient

Relationship	Percent (number)
Children	65.8 % (291)
Spouse	23.5 % (104)
Other relatives	5.2 % (23)
Neighbors/Friends	2.7 % (12)
Siblings	2.0 % (9)
Other	0.8 % (3)
Total	99 % (442)

Table 6: Dependent Children

Number of Dependent Children	Percent (number)
None	76.5% (328)
One	11.0 % (47)
Two	8.9% (38)
Three or more	3.7 % (16)
Total	100% (429)

Table 7: Living Arrangement

Living Arrangement	Percent (number)
Live with me	60.0 % (261)
Live independently	12.9% (56)
Live with spouse	12.0 % (52)
Live with other family	7.1 % (31)
Live in care facility	8.0 % (35)
Total	100 % (435)

Table 9: Source of Caregiver Assistance (multiple choices)

Rank	Helper	Number of Respondents
1	Children	39 % (134)
2	Paid caregiver/formal assistance	32 % (112)
3	Siblings	29 % (101)
4	Spouse	26 % (91)
5	Other relatives	16 % (54)
6	Neighbors/Friends	6 % (20)

Table 10: Common Types of Assistance (multiple choices)

Rank	Type of Assistance	Number of Respondents
1	Providing companionship, reassurance, emotional support	89 % (397)
2	Helping with medical appointment or medications	88 % (392)
3	Helping with housework, shopping, or meal preparation	87 % (386)
4	Helping with walking or transportation	80 % (356)
5	Helping with paperwork, bills, giving money, expenses	76 % (338)
6	Helping with bathing, dressing, feeding, or getting to the bathroom	55 % (246)
7	Changing diapers and cleaning up when the person has an “accident”	42 % (186)
8	Visiting and checking up by phone	40 % (180)
9	Lifting the person	29 % (128)

Table 11: Provision of High-Level Assistance by Living Arrangement (N=435)

	Lived with care recipients	Did not live with care recipients	Total percentage
Low-level	33.0 %	67.8 %	46.9 %
High-level	67.0 %	32.3 %	53.1 %
Total percentage	100 %	100 %	100 %

Table 12: Preferred Time Period for Outside Assistance (multiple choices)

Rank	Time Period	Number of respondents
1	During vacation	58 % (183)
2	In a crisis situation	55 % (176)
3	On weekends or holidays	34 % (108)
4	In the morning	33 % (104)
5	In the afternoon	26 % (83)
6	In the evening	23 % (79)
7	Overnight	20 % (64)

Table 13: Effects of Caregiving on Retirement Plan by Employment Status (N=394)

	Currently employed	Not employed	Total percentage
Retirement plan affected	18.4 %	33.6 %	26.9 %
Sometimes	7.5 %	15.0 %	11.7 %
Retirement plan not affected	74.1 %	51.4 %	61.4 %
Total percentage	100 %	100 %	100 %

Table 14: Feeling of Comfort in Handling Family Responsibilities by Employment Status (N=375)

	Currently employed	Not employed	Total percentage
Comfortable	62.9 %	76.9 %	70.7 %
Not comfortable	37.1 %	23.1 %	29.3 %
Total percentage	100 %	100 %	100 %

Table 15: Caregiver's Feelings toward Caregiving

Statement	% (N) Yes	% (N) sometimes	% (N) No	% (N) NA	Total N
1. I feel confident in providing care for this person	74% (313)	23% (97)	3% (11)	-	421
2. I am coping well with my present situation	61% (253)	32% (132)	7% (29)	-	414
3. I do more than my share of caring compared to other family members or other members of my support system	59% (240)	10% (42)	23% (94)	8% (32)	408
4. Caring for this person has negative effects on my physical health	25% (101)	38% (155)	38% (154)	-	410
5. Caring takes all of my time	24% (99)	24% (99)	52% (217)	-	415
6. I should be doing or should have done more for this person	21% (79)	30% (116)	49% (190)	-	385
7. Caring for this person has put a strain on my social life	35% (147)	35% (144)	30% (125)	-	416
8. Caring for this person has put a strain on my family relationship	25% (104)	28% (117)	41% (172)	6% (26)	419
9. Caring for this person has put a strain on my relationship with him/her	20% (83)	35% (146)	45% (189)	-	418
10. Caring for this person has affected my retirement plan	27% (110)	11% (46)	62% (250)	-	406
11. Caring for this person has affected my savings	27% (112)	11% (47)	61% (253)	-	412
12. I consider placing him/her in a care facility	12% (49)	21% (84)	60% (240)	7% (28)	401

Table 16: Effects of Caregiving on Employment

Statement	% (N) Yes	% (N) Sometimes	% (N) No	Total N
13. I used vacation, sick leave, or family leave for caregiving	44% (90)	22% (45)	34% (70)	205
14. I feel less productive and more distracted at work	25% (50)	29% (58)	46% (91)	199
15. I had to reduce my work hours to care for this person	28% (58)	12% (25)	60% (122)	205
16. I am thinking of quitting my job to care for this person	13% (26)	14% (29)	73% (148)	203

Table 17: Feeling of Productivity on Emotional Status of the Respondents (N=169)

	Productive	Sometimes	Less productive	Total percentage
Depressed	16.5 %	33.3 %	47.6 %	29.0 %
Not depressed	83.5 %	66.7 %	52.4 %	71.0 %
Total percentage	100 %	100 %	100 %	100 %

Table 18: Well-being of Caregivers

Statement	Percent Yes (N)	Percent No (N)	NA (N)	Total N
1. I enjoy spending time with my family	90 % (372)	5 % (19)	5 % (23)	414
2. My family gives me strength	80 % (324)	15 % (59)	5 % (24)	407
3. I have supportive friends	91 % (368)	9 % (38)	-	406
4. I am happy with my life	79 % (325)	21 % (87)	-	412
5. I can comfortably handle all my family responsibilities	69 % (274)	28 % (111)	3 % (10)	395
6. I feel emotionally well	80 % (321)	20 % (81)	-	402
7. I feel physically well	75 % (299)	25 % (100)	-	372
8. I feel financially stable	66 % (268)	34 % (141)	-	409
9. I am not doing enough to take care of myself	53 % (212)	48 % (186)	-	398
10. I feel depressed	27 % (100)	73 % (272)	-	372
11. I have increased my intake of alcohol, cigarette, etc.	7 % (26)	77 % (307)	16 % (65)	398

Table 19: Financial Stability by the Number of Dependent Children (N=395)

	No Children	1-2 Children	More than 3 Children	Total Percentage
Financially stable	68.9 %	62.2 %	21.4 %	65.8 %
Not Stable	31.1 %	37.8 %	78.6 %	34.2 %
Total Percentage	100 %	100 %	100 %	100 %

Table 20: Nonparametric Correlation

	1	2	3	4	5	6	7	8	9	10	11
1. Depressed	1										
2. Happy with life	-.542**	1									
3. Enjoy with family	-.208 **	.344 **	1								
4. Not taking care of myself	.341**	-.312 **	-.077	1							
5. Emotional well-being	-.645 **	.657 **	.255 **	-.355 **	1						
6. Have supportive friends	-.172 **	.228 **	.107	-.065	.206 **	1					
7. Family give strength	-.253 **	.322 **	.517 **	-.225 **	.375 **	.204 **	1				
8. Comfortably handle family responsibilities	-.395 **	.521 **	.286 **	-.267 **	.468 **	.230 **	.283 **	1			
9. Financial stability	-.237 **	.222 **	0.87	-.246 **	.261 **	.118	.226 **	.337 **	1		
10. Physical well-being	-.491 **	.554 **	.303**	-.403 **	.558 **	.201 **	.218 **	.462 **	.270 **	1	
11. Increased alcohol	.183 **	-.216 **	-.117	.176 **	-.281 **	-.03	-.183 **	-.188 **	-.181 **	-.258 **	1

** Correlation is significant at the .01 level

Table 21: Depression and Happiness in Life (N=360)

	Depressed	Not depressed	Total percentage
Happy with life	40.2 %	91.4 %	78.3 %
Not happy with life	59.8 %	8.6 %	21.7 %
Total percentage	100 %	100 %	100 %

Table 22: Depression and Physical Health (N=358)

	Depressed	Not depressed	Total percentage
Physically well	40.4 %	88.3 %	75.7 %
Physically not well	59.6 %	11.7 %	24.3 %
Total percentage	100 %	100 %	100 %

Table 23: Depression and Family Relationship (N=339)

	Depressed	Not depressed	Total percentage
Enjoy being with family	87.2 %	97.6 %	95.0 %
Do not enjoy with family	12.8 %	2.4 %	5.0 %
Total percentage	100 %	100 %	100 %

Table 24: Emotional Status by the Availability of Additional Help

	Had additional help	No additional help	Total Percentage	Total N
Not emotionally well	16.8 %	33.8 %	20.1 %	402
Family did not give me strength	16.8 %	33.8 %	20.1 %	402
Not Financially stable	31.1 %	47.6 %	34.5 %	409
Depressed	23.2 %	42.9 %	26.9 %	372
Not physically well	21.8 %	37.8 %	25.1%	399

Table 25: Feeling of Guilt by Availability of Additional Help (N=385)

	Had additional help	No additional help	Total percentage
No feeling of guilt	45.4 %	64.2 %	49.4 %
Sometimes	31.9 %	23.5 %	30.1 %
Feeling of guilt	22.7 %	12.3 %	20.5 %
Total percentage	100 %	100 %	100 %

Table 26: Strain on Relationship with Care Recipient by the Availability of Additional Help (N=418)

	Had additional help	No additional help	Total percentage
No strain	48.0 %	34.5 %	45.2 %
Sometimes	35.0 %	34.5%	34.9 %
Had strain	16.9 %	31.0 %	19.9 %
Total percentage	100 %	100 %	100 %

Table 27: Feelings toward Caregiving and Availability of Additional Help (N=376)

	Had additional help	No additional help	Total percentage
I do not do my share of caring	27.9 %	11.8 %	25.0 %
Sometimes	13.0 %	2.9 %	11.2 %
I do more than my share of caring	59.1%	85.3 %	63.8 %
Total Percentage	100 %	100 %	100 %

Table 28: Well-being of the Respondents by Living Arrangement

	Living together	Not living together	Total percentage	Total N
Not happy with life	26.7 %	12.8 %	21.0 %	404
Not doing enough to take care of myself	41.4 %	55.7 %	47.2 %	390
Not emotionally well	26.3 %	10.5 %	19.8 %	394
Not financially stable	39.4 %	26.7 %	34.3 %	402
More likely depressed	33.3 %	16.4 %	26.6 %	365

Table 29: Knowledge of Home Care Services by the Availability of Additional Assistance (N=372)

	Had additional help	No additional help	Total percentage
Know about services	82.6 %	61.9 %	78.0 %
Does not know about services	17.4 %	38.1 %	22.0 %
Total percentage	100 %	100 %	100 %

Table 30: Types of Home Care Services Received (multiple choices)

Rank	Type of formal services received	Number of respondents	Frequency per week
1	Adult day care/respite services	36 % (85)	3.7
2	Personal care services	28 % (66)	4.5
3	Transportation/Handivan	28 % (66)	2.8
4	Home delivered meals	25 % (60)	4.2
5	Public assistance (Medicaid, food stamps, housing, etc.)	21 % (51)	-
6	Homemaker services	21 % (50)	3.5
7	Care plan services	19 % (46)	-
8	Health Maintenance	19 % (46)	2.8
9	Chore services	15 % (37)	2.0
10	Counseling/support services	11 % (27)	1.7
11	Nursing services	10 % (24)	2.3
12	Senior companion services	10 % (24)	1.4

Table 31: Rank of Needed Services (multiple choices)

Rank	Type of Services Needed	Number of respondents
1	Information, education, and training about caregiving	47 % (176)
2	Health maintenance such as an exercise program	38 % (142)
3	Adult day care/health and respite programs	37 % (141)
4	Tax assistance (state tax deduction or credits)	32 % (122)
5	Personal and family counseling, advice, mediation, and support groups	30 % (112)
6	Senior companion	29 % (108)
7	Financial support – cash or coupon to purchase services, etc.	28 % (107)
8	Homemaker/chore services	27 % (102)
9	Care plan (assistance in making a care plan and exploring care options)	26 % (98)
10	Financial and legal consultation (banking, estate planning, wills, advance directives, guardianship, etc.)	24 % (91)

Table 32: Caregiving Stages

Stages	Description	Percentage (number)
Marker 1	Performing caregiving tasks	6 % (22)
Marker 2	Self-identification as caregiver	19 % (72)
Marker 3	Performing personal care	13 % (47)
Marker 4	Assistance and formal service use	33 % (124)
Marker 5	Consideration of nursing home replacement	10 % (39)
Marker 6	Institutionalization	6 % (24)
Marker 7	Termination of caregiving tasks	13 % (48)
	Total	100% (376)

Table 33: Ranking of Needs Expressed by the Respondents in Various Markers

Needs	Total	M-1	M-2	M-3	M-4	M-5	M-6	M-7
Information, education, and training about caregiving	1	1	1	1	1	2	2	1
Health maintenance such as an exercise program	2	2	2	4	4	3	3	
Adult day care/respite services	3		4	3	3	1		
Tax assistance (state tax deduction or credits)	4		5	2	2			3
Personal and family counseling, advice, mediation, and support groups	5	4	3				1	
Homemaker/chore services		3				4		2
Care plan						5		
Home modification, safety devices, assisted devices for example, walker, wheelchair, lifts, etc.								5
Senior companion		5		5	5			
Financial consultation (banking, estate planning), legal consultation)							4	4
Financial support – cash or coupon to purchase services, pay family caregiver, and/or equipment, public assistance, etc.							5	

Note: M-1,2...7 indicate caregiving markers/stages

Table 34: The Respondent's Preparedness for the End-of-life Plan

Type of Plan	Percent yes (number)	Percent no (number)	Total number of respondents
Will	62 % (248)	28 % (151)	399
Living Trust	53 % (217)	47 % (191)	408
Advance Directives	52 % (190)	48 % (177)	367
Power of Attorney	52 % (210)	48 % (193)	403
Funeral Arrangement	36 % (142)	64 % (249)	391

Table 35: The Care Recipient's Preparedness for the End-of-Life Plan

Type of Plan	Percent yes (number)	Percent no (number)	Percent don't know (number)	Total number of respondents
Will	75 % (294)	19 % (75)	6 % (22)	391
Living Trust	65 % (253)	29 % (115)	6 % (24)	392
Advance Directives	66 % (252)	21 % (78)	13 % (50)	380
Power of Attorney	74 % (298)	19 % (77)	7 % (26)	401
Funeral Arrangement	60 % (233)	32 % (124)	8 % (32)	389

Table 36: Private LTC Insurance

		Percentage of Yes (number)	Percentage of No (number)	Total number
Possession of private LTC insurance		32% (141)	68% (294)	435
Rank	Reasons for not having LTC insurance	Percentage (number), N=252		
1	Can't afford to buy	52 % (132)		
2	To early to think about it	14 % (34)		
3	Considering/studying	10 % (26)		
4	Don't know much about it	8 % (20)		
5	Not needed	4 % (11)		

Table 37: Long-Term Care (LTC) Insurance by Ethnicity (N=433)

	Caucasian	Asian	Hawaiian/Part-Hawaiian/Pacific Islanders	Other	Total percentage
Have LTC insurance	20.5 %	39.9 %	13.5 %	26.7 %	32.6 %
No LTC insurance	79.5 %	60.1 %	86.5 %	73.3 %	67.4 %
Total percentage	100 %	100 %	100 %	100 %	100 %

Table 38: Long-Term Care (LTC) Insurance by Educational Level (N=432)

	Less than college degree	More than college degree	Total percentage
Have LTC insurance	23.5 %	38.7 %	32.4 %
No LTC insurance	76.5 %	61.3 %	67.6 %
Total percentage	100 %	100 %	100 %

Table 39: Support for State-Sponsored LTC Insurance

Support State-Sponsored LTC Insurance	Percentage (number), N = 419
Yes	35 % (145)
No	15 % (62)
Not sure	51% (419)

Table 40: Preference for Consumer-Directed Care

Rank	Preference	Percentage (number) N=379
1	I want cash for the needs of the person I care for (services & goods), and I am willing to manage the cash	57 % (214)
2	I want a professional to assist me in finding and paying caregivers	18 % (67)
3	I would like to receive coupons for services of my choice from participating providers	17 % (63)
4	I want an agency to send out workers and to supervise them	7 % (28)
5	I want to select the services, but I want a professional to manage the cash.	2 % (7)

Survey Instrument

ID number _____

Part 1: Assessment of Caregiver

1. Are you currently helping, keeping an eye on, or providing care to someone who is 60 years old or older and who has some physical and/or mental problems? (Please check the appropriate answer).
☐ Yes (skip question 2 & 3) ☐ No
2. If no, did you care for someone in the past 2 years?
☐ Yes ☐ No (go to question 29)
3. If yes, what was the reason you stopped helping or caring for this person?
☐ The person passed away.
☐ The person recovered and does not require any more help or care at this time.
☐ I could no longer provide care due to my own illness.
☐ The person moved to a different location.
☐ I moved to a different place.
☐ Other (specify) _____.

For the following questions (Q4 – Q12), please think about the person you are caring for now. If you are no longer caring for an elder, think back to the time you were caring for an elder and answer the questions based on your past experience.

4. Are you his/her...?
☐ Husband/wife, companion
☐ Mother, father, mother-in-law, father-in-law
☐ Son, daughter, son-in-law, daughter-in-law
☐ Sister, brother, sister-in-law, brother-in-law
☐ Other relatives (specify) _____
☐ Neighbor/Friend
☐ Other (specify) _____
5. Where does he/she live?
☐ with me ☐ independently ☐ with his/her spouse
☐ with other family or relatives
☐ in a care home, nursing home or assisted living facility
6. Do you consider yourself a “caregiver?”
☐ Yes ☐ No
7. How long have you been helping this person? _____ yrs.

8. Who else provides care to this person besides you?
- ☐ Husband, wife, companion
 - ☐ Mother, father, mother-in-law, father-in-law
 - ☐ Son, daughter, son-in-law, daughter-in-law
 - ☐ Sister, brother, sister-in-law, brother-in-law
 - ☐ Other relative (specify) _____
 - ☐ Neighbor/Friend
 - ☐ Paid caregiver
 - ☐ Nobody besides me
 - ☐ Other (specify) _____
9. Which kind of help do you provide? (Please check all the things you do for the elder).
- ☐ Providing companionship, reassurance, and emotional support.
 - ☐ Visiting and checking up by phone.
 - ☐ Helping with paperwork and bills, giving money, helping pay expenses.
 - ☐ Helping with medical appointments or medications.
 - ☐ Helping with housework, shopping, or meal preparation.
 - ☐ Providing help with walking or transportation.
 - ☐ Helping the person with bathing, dressing, feeding, or getting to the bathroom.
 - ☐ Lifting the person.
 - ☐ Changing diapers and cleaning up when the person has an "accident".
 - ☐ Other (specify) _____.
10. In an average week, how many hours do you help with the above tasks?
_____ hours a week.
11. Do you need help with caring for the following time period? (Please check all that apply).
- ☐ No ☐ In the morning ☐ In the afternoon ☐ In the evening ☐ Overnight
 - ☐ On weekends or Holidays ☐ In a crisis situation ☐ During vacation
12. The following statements reflect how people sometimes feel when taking care of another person. Please read each statement below, and circle the appropriate answer. There are no right or wrong answers, and if the question is not appropriate for you, just skip it.

In general,					
1	I feel confident in providing care for this person.	Y	N	Sometimes	
2	Caring for this person has negative effects on my physical health.	Y	N	Sometimes	
3	I am coping well with my present situation.	Y	N	Sometimes	
4	I should be doing or should have done more for this person.	Y	N	Sometimes	
5	Caring for this person has put a strain on my social life.	Y	N	Sometimes	
6	Caring for this person has put a strain on my family relationship.	Y	N	Sometimes	N/A
7	Caring for this person has put a strain on my relationship with him/her.	Y	N	Sometimes	
8	Caring takes all of my time.	Y	N	Sometimes	
9	I do more than my share of caring compared to other family members or other members of my support system.	Y	N	Sometimes	N/A
10	Caring for this person has affected my retirement plan.	Y	N	Sometimes	
11	Caring for this person has affected my savings.	Y	N	Sometimes	
12	I consider placing him/her in a care facility.	Y	N	Sometimes	N/A
* If you are employed, please check the following statements.*					
13	I used vacation, sick leave, or family leave for caregiving.	Y	N	Sometimes	
14	I feel less productive and more distracted at work.	Y	N	Sometimes	
15	I had to reduce my work hours to care for this person.	Y	N	Sometimes	
16	I am thinking of quitting my job to care for this person.	Y	N	Sometimes	

If you are no longer providing care, or the care is provided by a care home, nursing home, assisted living facility, please go to question 17.

Part 2: Formal Services

13. Do you know how to get information about services to help you or your loved one?
☐ Yes ☐ No
14. Is the person you care for currently receiving the following services?

Please mark all that apply.	How many times/week?	
<input type="checkbox"/> None.		
<input type="checkbox"/> Home-delivered meals.		Don't know
<input type="checkbox"/> Adult day care/health services, respite care (temporary break from caregiving responsibility).		Don't know
<input type="checkbox"/> Counseling/support services.		Don't know
<input type="checkbox"/> Assisted transportation or Handivan.		Don't know
<input type="checkbox"/> Bathing and personal care services.		Don't know
<input type="checkbox"/> Nursing services.		Don't know
<input type="checkbox"/> Homemaker services (light cleaning, shopping, cooking, etc.).		Don't know
<input type="checkbox"/> Chore services (heavy cleaning, yardwork, etc.)		Don't know
<input type="checkbox"/> Senior companion (visitation by peers, volunteers).		Don't know
<input type="checkbox"/> Health maintenance such as exercise program.		Don't know
<input type="checkbox"/> Care plan service (you have a social worker/case manager assigned to you to assist with coordinating services).		
<input type="checkbox"/> Public assistance (Medicaid, food stamps, housing, etc.)		
<input type="checkbox"/> I don't know what services are being used.		
<input type="checkbox"/> Other (specify)_____		

15. How did you find out about the services that this person is using or has used?
 (Please check all that apply).
☐ Newspaper ☐ TV/radio ☐ Brochure/pamphlet/flyer/newsletter
☐ Family members/friends ☐ Community service providers
☐ Information and referral services at the Area Agency on Aging
☐ Doctors/nurses ☐ Other (specify) _____
16. If you haven't used services, what is the main reason for not using them?
☐ I don't know what services are available.
☐ I don't know how to get information about the services.
☐ I don't have money to pay for services.
☐ I don't have a telephone to arrange the service.
☐ I don't want strangers to come into my house.
☐ Service hours provided don't meet my needs.
☐ I don't need outside help at this time.
☐ Other (specify)_____.
17. Have you ever used respite or adult day care/day health programs?
☐ Yes (go to question 19) ☐ No

18. If no, what is the main reason for not using these programs?
- ☐ I don't know about respite, adult day care/day health programs.
 - ☐ It is expensive.
 - ☐ I don't have time to take this person to these programs.
 - ☐ I don't have a transportation to take this person to these programs.
 - ☐ Service hours provided don't meet my needs.
 - ☐ The person I am caring for does not want to go to these programs.
 - ☐ I don't need outside help at this time.
 - ☐ Other (specify)_____.

Part 3 Your Current Needs

19. The following is a list of statements that reflect how people sometimes feel. Please read each statement below, and indicate how you feel about each statement in general. (Please circle the appropriate answers).

In general,				
1	I am happy with my life.	Y	N	
2	I enjoy spending time with my family.	Y	N	N/A
3	I am not doing enough to take care of myself.	Y	N	
4	I feel emotionally well.	Y	N	
5	I have supportive friends.	Y	N	
6	My family gives me strength.	Y	N	N/A
7	I feel I can comfortably handle all my family responsibilities.	Y	N	N/A
8	I feel financially stable.	Y	N	
9	I feel depressed.	Y	N	
10	I feel physically well.	Y	N	
11	I have increased my intake of alcohol, cigarettes, etc.	Y	N	N/A

20. When you consider your life today, what three things would you like to do more of?
1. _____
 2. _____
 3. _____
21. In your opinion, which services would be helpful to **YOU** now? (Please check all that apply).
- ☐ None.
 - ☐ Personal and family counseling, advice, mediation, and support groups.
 - ☐ Information, education, and training about caregiving.
 - ☐ Home-delivered meals.
 - ☐ Assisted transportation or Handi-van.
 - ☐ Bathing and personal care services.
 - ☐ Rehabilitation services such as occupational or physical therapy
 - ☐ Health maintenance such as exercise program.
 - ☐ Homemaker/chore services (light cleaning, shopping, cooking, etc.)
 - ☐ Adult day care/health services, respite care (temporary break from caregiving responsibility).
 - ☐ Care plan service (assistance in making a care plan and exploring care options).
 - ☐ Senior companion.
 - ☐ 24-hour toll-free "helpline" services.

- ☐ Help with admitting this person to a long-term care facility.
- ☐ Financial consultation (banking), legal consultation (estate planning).
- ☐ Financial support - cash or coupon to purchase services, pay family caregiver, and/or equipment, public assistance (Medicaid, food stamps, housing, etc.).
- ☐ Tax assistance (state tax deduction or credits).
- ☐ Home modification, safety devices, assisted devices for example, walker, wheelchair, lifts, etc.
- ☐ Other (specify) _____.

22. Have you made any of the following arrangements? (Please circle the appropriate answers).

	Yourself?		The Person you care for?		
Will	Yes	No	Yes	No	Don't know
Living trust	Yes	No	Yes	No	Don't know
Advance directives	Yes	No	Yes	No	Don't know
Power of attorney	Yes	No	Yes	No	Don't know
Funeral arrangement	Yes	No	Yes	No	Don't know

23. Do you have private Long Term Care insurance for yourself?

- ☐ Yes ☐ No

24. If no, why not?

25. Would you be willing to pay into a State-sponsored Long-Term Care Insurance Program?

- ☐ Yes ☐ No ☐ Unsure

26. If yes, what is a reasonable amount per month? \$ _____

27. If the person you care for were to receive \$1,000 for services a year, which arrangement would you prefer? (Please select **only one** answer).

<input type="checkbox"/>	I want cash for the needs of the person I care for (services & goods), and I am willing to manage the cash.
<input type="checkbox"/>	I want to select the services, but I want a professional to manage the cash.
<input type="checkbox"/>	I want a professional to assist me in finding and paying caregivers.
<input type="checkbox"/>	I want an agency to send out workers and to supervise them.
<input type="checkbox"/>	I would like to receive coupons for services of my choice from participating providers.

28. What advice would you give to new family caregivers?

Part 4: About You

29. Your age: _____
30. Which ethnicity do you identify most with?
☐ Afro-American ☐ Caucasian ☐ Hispanic ☐ Native American
☐ Filipino ☐ Chinese ☐ Japanese ☐ Korean ☐ Asian Indian
☐ Vietnamese ☐ Cambodian ☐ Laotian ☐ Other Asian _____
☐ Hawaiian/Part Hawaiian ☐ Samoan ☐ Tongan ☐ Micronesian
☐ Other (specify) _____
31. Your marital status:
☐ Married or living with partner ☐ Widow/widower
☐ Separated or divorced ☐ Single, never married
32. How many dependent children do you have?
☐ None ☐ One ☐ Two ☐ Three ☐ Four or more
33. What are their ages? _____
34. Are you currently employed?
☐ Full-time ☐ Part-time ☐ Retired ☐ Not employed
35. What was the last grade of school you completed?
☐ Less than high school ☐ High school graduate
☐ Some college ☐ College graduate ☐ Post-graduate

Thank you very much for participating in our survey.